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A Qualitative Analysis of Health Literacy Issues among Women with Visual Impairments

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Abstract

The purpose of this secondary analysis using qualitative description was to explore health literacy from the healthcare experiences of women with permanent visual impairments. Interviews from a sample of 15 community-residing women age 44 to 79 years with permanent visual impairments who had participated in a larger grounded theory study were analyzed. The 15 women were interviewed twice, with each interview lasting up to three hours. The audio-taped interviews were transcribed verbatim and analyzed using qualitative content analysis. Using the Institute of Medicine's definition of health literacy, the women's experiences were categorized into their ability to obtain, process, and understand health information. Their perceptions of the factors that influenced their health literacy were also explored. The women voiced that barriers to their ability to gain information in a format amenable to their processing skills, combined with barriers arising from healthcare providers' attitudes, undermined their ability to build health literacy capacity.

Keywords

Visual impairment; disability; aging; aging with disability; women

Problems surrounding *health literacy*, a person's ability to "obtain, process and understand basic health related information and services needed to make appropriate health decisions" (Ratzan & Parker, 2000, p. vi), are estimated to be responsible for nearly 70 billion dollars in healthcare related costs (Zarcadoolas, Pleasant, & Greer, 2006). Lapses in appropriate communications between health care providers and the people they serve further exacerbate the problem of low health literacy in the provision of effective health care. According to Thorne, Harris, Majoney, Con, and McGuinness (2004), people with chronic conditions that seek healthcare experience problems that include the perceptions that providers withhold information, interact disrespectfully, and block access to expertise. The aging, visually impaired population may be at risk for low health literacy and poor communication with health care providers. Despite this risk, little attention has been paid to the health literacy needs of those aging with visual impairments. The purpose of this paper is to report on a qualitative analysis of how 15 women with visual impairments (VIs) attempted to promote their health in the U.S. healthcare system. This analysis was performed based on the current conceptualization of health literacy as proposed by the Institute of Medicine [IOM] (2004).

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BACKGROUND

Nearly one million Americans over the age of 40 are legally blind, and another 2.4 million have low vision (The Eye Disease Research Prevalence Group, 2004). These estimates are based on definitions, shown in Table 1, provided by the World Health Organization and the United States (U.S.) medical consensus. Overall, over 3 million people in the U.S. have VIs, including macular degeneration (54%), the leading cause of blindness, and cataracts (50%), the leading cause of low vision. Given that VIs increase with age, The Eye Disease Research Prevalence Group estimated that by the year 2020, the number of persons over age 40 in the U.S. with severe VIs would be 5.5 million. When put in a global context, a staggering 75 million people will be living with VIs by 2020 (World Health Organization [WHO], 2009). In the U.S., this translates to an estimated 35.4 billion dollar annual cost, which includes direct medical costs, other direct costs, and productivity loss (Rein, Zhang, Wirth, et al., 2006). Financial burdens operate at the personal level, too. Increasing rates of VIs in the U.S. correspond to lower income levels (United States Department of Health and Human Services/Centers for Disease Control [USDHHS/CDC], 2006). If the results of a recent meta-analysis are correct that the odds ratio of blind women to men is 1.43 (95% CI, 1.33-.153), then women disproportionately bear the costs related to VIs (Abou-Gareeb, Lewallen, Bassett, & Courtright, 2001).

Health outcomes and visual impairment

As our population ages, it is imperative that attention be paid to the healthcare needs of those with VIs. Although many people with severe VIs live productive, healthy lives, others have difficulty promoting and maintaining their health. VIs predict an increased mortality; those with chronic diseases such as diabetes, hypertension, heart disease, and stroke have higher mortality if they also have VIs compared to those with chronic diseases and no VIs (Cugati, Cumming, Smith, Burlutsky, Mitchell, & Wang, 2007). Moreover, those with VIs are at a higher risk for institutionalization, disability, and death (Whitson, Cousins, Burchett, Hybels, Pieper, & Cohen, 2007). Among people with VIs who are considered legally blind ($\leq 6/60$ [$\leq 20/200$]), there is a 78% likelihood that they have difficulty with activities of daily living (Sloan, Ostermann, Brown, & Lee, 2005). These difficulties may have contributed to the findings of one study of over 3,500 people under the age of 80 indicating that persons with VIs had significantly lower self-rated health, which was a strong predictor of mortality outcomes (Wang, Mitchell, & Smith, 2000). Strategies for improving the overall health outcomes of persons with VIs are needed, and factors that may influence their health beyond the direct influence of vision-related pathology must be considered. In other words, there might be factors amenable to interventions that do not require a change in visual acuity.

Understanding health literacy

Healthy People 2010 included health promotion goals for persons with disabilities, including the prevention of co-morbidities (USDHHS, 2000). One possibility for reaching those objectives and improving the health of persons with VIs may lie in the advance of health literacy. Health literacy has been associated with knowledge about chronic disease (Gazmarian, Williams, Peel, & Baker, 2003) and pharmacological treatment (Fang, Machtinger, Wang, & Schillinger, 2006), as well as health care costs and utilization rates (Baker, Gazmararian, Williams, et al., 2002; Friedland, 1998).

Although *literacy* generally refers to the ability to read and solve problems, *health literacy* is defined as the ability to “obtain, process and understand basic health-related information and services needed to make appropriate health decisions” (Ratzan & Parker, 2000, p. vi). The Institute of Medicine (IOM, 2004) adopted this definition and proposed that further work be done to measure health literacy in ways consistent with the definition that go beyond the

ability to talk, read, and calculate. Hence, health literacy goes beyond the concept of literacy, which is comprised of oral literacy and print literacy; oral literacy is the ability to listen and speak effectively and print literacy is the ability to read, write, and calculate (IOM, 2004).

In the IOM Health Literacy Model with Potential Intervention Points, health literacy is influenced by environmental factors within culture and society, educational systems, and healthcare industries (Figure 1). These factors may directly affect health literacy or interact to influence health literacy. For instance, shared values within a society influence which people are able to gain access to learning resources needed for health. The societal view on the nature of being disabled influences whether information was given to people with VIs when in a healthcare system. Further, the nature of past educational experiences of people with VIs may influence their ability to use those skills when confronted with health issues later in life.

In the context of disability, the term *health literacy* should be used with caution because early conceptualizations of health literacy may highlight issues related to functional literacy—the ability to read written text. As defined by the Institute of Medicine, health literacy is congruent with the goals of people with disabilities seeking to overcome barriers in obtaining health information and adequate healthcare (Rosenbloom & Schneiderman, 2007). If a narrow definition of health literacy were used, focusing only on reading to understand directions, and hence compliance with provider medical edicts (Tones, 2002), then interventions designed to improve health literacy might not be recommended for persons with VIs or any type of disability. Instead, health literacy, the capacity of persons with VIs to obtain and analyze health information to gain greater control over their health, is an important and attainable goal (Nutbeam, 1998).

Health literacy and visual impairment

Educators have long considered literacy a high priority for those with VIs (Argyropoulos & Martos, 2006; Rex, 1989). Literacy is a key skill for persons with VIs living in today's world (Schroeder, 1989). Among persons with VIs, however, there are differences in the mediums or formats in which information is processed, unlike sighted persons who are educated in one primary text-based medium (Rex, 1989). Success in literacy for those with VIs is dependent upon matching the best medium with the person's accommodation needs (Koenig, Sanspree, & Holbrook, 2007). Indeed, the proportion of persons with VIs who are visual, auditory, and/or Braille readers varies. In other words, preferences for different types of informational mediums are not uniform among persons with VIs.

There were no studies found that directly addressed or measured health literacy among persons with VIs. Most studies of persons with VIs that were found, besides those focused on curing or treating eye disease, focused on the meaning of the experiences of losing vision (Allen, 1989; Brouwer, Winding, & Hanneman, 2005; Bullington & Karlson, 1997; Moore, 2000; Moore & Miller, 2003) or adaptation to vision loss (Brennan & Cardinali, 2000; Tolman, Hill, Kleinschmidt, & Gregg, 2005). Other studies focused on the provision of services to persons with VIs to improve health outcomes. In a meta-analysis of the health information needs of persons with VIs, Beverley, Bath, and Booth (2004) identified 16 research studies that met search criteria for health information, intervention, and VIs. These studies focused primarily on health promotion or eye-related education. There were no studies on ways to adapt information to the perceived needs of people with VIs or their informational needs related to specific medical conditions (e.g., cancer) that may be unrelated to the cause of their visual impairment. Researchers have worked to adapt information into the appropriate formats (e.g., Braille), but they have neither investigated if

that content was applicable to their participants' lives nor measured the participants' ability to process and understand the content.

The purpose of this study was to describe the health literacy experiences of women with VIs. The goal was to provide a descriptive account of health literacy that might be considered when providing health care and designing future measurement tools/interventions.

METHODS

Design Overview

This study is a secondary analysis of data collected in an ongoing larger qualitative study about how the timing of impairment in women's lives affects their ability to promote health. This secondary analysis using qualitative description (Sandelowski, 2000) focused on those women with VIs who participated in the larger study and reported disability related to vision. The qualitative content analysis (Miles & Huberman, 1994) was guided by the definitions supplied in the IOM's (2004) model of health literacy.

Setting and Sample

Fifteen women with VIs (e.g., who self-reported as legally blind despite correction with resultant low or no vision) participated in the larger study, which currently consists of 45 women with varying types of permanent physical and sensory impairments. After approval from the local Institutional Review Board, all of the women were recruited purposefully based on self-reported physical and/or sensory impairment. The purposive sample of women residing within their respective communities were recruited through word of mouth contacts, primarily within the local disability community, and were paid \$10.00 for each of the two interviews.

The 15 women with VIs ranged in age from 44 to 79 years. Fourteen women reported to be Anglo, whereas one reported to be Native American. Five of the women were married, one had never married, seven were divorced, and two were widowed. Nine of the women had children. The women were highly educated; nine had graduate degrees and four had bachelor's degrees, but only five were currently working and only one worked full-time. Of the women who were not working, eight stated that they were retired from the workforce due to disability. The age at which they stopped working ranged from 31 to 73 years; eight stopped working before reaching age 65. Eight of the women stated they were currently on Medicare and three had private insurance. Three of the women stated they were currently unable to meet their financial needs.

In this sample of women with VIs, one woman reported having only central vision, nine reported the ability to see only shapes and lights, and five reported having no vision. The reasons for their VIs ranged from macular degeneration and ocular hypertension to diabetic retinopathy and retinopathy of prematurity. The onset ranged from birth to 64 years of age. The women had lived with their VIs from age 3 to age 58 years. Fourteen of the women reported having some type of co-morbid condition; common problems were hypertension, cancer, and diabetes. Other problems mentioned were kidney failure, tuberculosis, fibromyalgia, chronic back pain, pulmonary emboli, and status post-kidney and pancreatic transplants. Eleven of the women were currently using either a white or a mobility cane. Four women used a guide dog, 13 relied on computer aids for communications, and five hired readers to assist them. No women were able to drive automobiles.

Data Measurement and Analysis

The interview and demographic data for the 15 women in this study with the aforementioned VIs were extracted from the larger data set. The demographic data were entered into SPSS 14.0 and descriptive data were generated. The interview data were transcribed verbatim, and then checked for accuracy. All identifying information was deleted.

Data Collection—All 15 women with VIs were interviewed twice at their homes or businesses. During the first interview, the informed consent form was read to each participant, and then using a straight edge, the women signed the forms. Next, the demographic questions were read to the participants and the forms were completed by the PI. The interviews, which were audio-recorded, were open ended and minimally structured. The first interview, which lasted from 1 to 3 hours, was a life course review of how the participants had taken care of themselves since the onset of their impairments. The women were asked to talk about what was going on in their lives when their impairments started, and then were asked to work their way forward in time, talking about the salient events in their lives. The second interviews were used to clarify any remaining questions stemming from the first interview. Both interviews were used to explore developing concepts in the larger grounded theory study.

Data Analysis—After transcription was complete and the data were checked for accuracy, the interview data for the 15 women with VIs in this study were removed from the larger data set. A qualitative content analysis was conducted (Miles & Huberman, 1994), categorizing information obtained into categories as defined by the health literacy model. Each content area was synthesized and described according to the women's experiences in each category. Specifically, the qualitative content analysis consisted of the following the steps:

1. The data were read in their entirety.
2. A matrix was created containing each of the concepts used to define health literacy in the IOM's model: Influences on health literacy, ability to process, ability to understand, and ability to access. These concepts were placed along the top edge of large foam boards.
3. Data were labeled, cut out, and sorted. Data were then placed on the foam boards beneath the concept to which they corresponded. If any segment of the data applied to multiple concepts, then it was placed in all the categories that were applicable.
4. After all of the data were sorted into the concepts, the data were merged into categories within each of the concepts to aggregate and understand the women's experience with health literacy.
5. The investigators met and discussed the findings to ensure understanding and consensus.
6. Descriptions of the categories were detailed under each concept.

RESULTS

The results of this study are presented in the context of the IOM model of Health Literacy (2004) as displayed in Figure 1. Influences on health literacy, as well as the concepts used to define health literacy, including the ability to obtain, process, and understand health information, are discussed in relation to the issues that the women described as salient in their acquisition of health.

Health Literacy

Influences on Health Literacy

Factors in the Healthcare System: Factors in the healthcare system that influenced the women's ability to build health literacy were linked to provider interactions and modes of operation. The women stated that providers' assumptions about women with VIs, knowledge about VIs, and communication skills were the provider interactions that influenced their health literacy. They stated that the routine reliance on paperwork and set time schedules were factors that influenced the modes of operation.

The women stated that during interactions with providers they were treated differently than other patients because of the assumptions that providers made about people with VIs. The first assumption was that women with VIs could not perform self-care. For instance, a participant reported that after surgery, she was not given control of her intravenous pain medication because she was visually impaired. She stated, "Most people on the floor would be given the button to push for pain medication and there's this assumption that because you're blind, you can't push that." The second assumption mentioned was that women with VIs had personal caregivers. For example, a participant who lived independently in her home was given medications before a diagnostic procedure. She stated that she asked the nurse, "Okay, could you give me the instructions for taking this?" The nurse responded, "Well, it has it on there, it says on there. Have whoever takes care of you do this." The third assumption was that VI was an ailment, a medical problem that needed medical attention in every provider encounter. As one participant stated, "Doctors see you as the blind person, not the person who happens to be blind." Another stated, "Blindness just happens to be a characteristic. It is not a diagnostic criterion." The final assumption was that they were without cognitive skills and thus reliant on government assistance. A participant summed it up when she stated, "I mean there is an assumption that...she's probably on welfare or she can't express what's wrong with her and if she does express what's wrong with her, she's probably wrong about it. I mean, she probably doesn't get what's happening."

Providers' skills in communicating with the women were also an interaction that influenced health literacy. The women wanted to be informed about what was being done to them, where they would be going, and how things might feel. A participant stated, "Tell me what you're going to do to me before you do it. It makes a lot happier, more compliant patient." The women felt that such information should be provided to all patients, regardless of disability status. However, for the women with VIs in this study, instructions were not only needed when procedures were done, but also before and after procedures. The women pointed out that they also needed to know "when it's time to go or when they want you to put the little gown on." They needed to know the routine things that were expected; the things most people pick-up from visual cues. Further, the women wanted to be informed in a way that was not dismissive or without respect. For instance, a woman with no vision stated, "But I mean he was thumbing through my chart. He was looking down like this most of the time and just... and looking everywhere. Out the window. You know you can just tell by how people's voice sounds if they're looking at you or not."

The final provider interaction that influenced health literacy was related to provider knowledge about VIs. The women perceived that providers' knowledge of VIs colored how they communicated and what assumptions they conveyed. The women felt that unless providers were exposed to people with VIs, they did not know how to act around them. One participant stated, "Some get very uncomfortable with blind people because they've never been around them. They haven't been exposed to them." This level of discomfort was noticeable to the women. When providers showed confidence in the women's abilities, the women's feelings that they could learn and become health literate improved. For instance, a

woman with a history of breast cancer stated, “he made me feel really at ease right away. We talked about some ways that I could measure safer, example, liquid Tylenol.”

The modes of operation that influenced the women’s health literacy were the heavy reliance on paperwork and set time schedules. First, the women overwhelmingly reported that there were “a lot of paperwork barriers.” The women reported being asked to complete forms that they could not see. When they asked for accommodations (e.g., for someone to help them complete the forms), they reported that receptionists either read personal health history forms aloud to them in busy waiting rooms or asked other people, such as their drivers, to read the forms to them. These accommodations were notable violations of the Privacy Rule of 2003 that enforces the Health Insurance Portability and Accountability Act of 1996 (United States Department of Health and Human Services [USDHHS], 2003). One woman with a VI described an event in which her taxi cab driver was asked by a clinic receptionist to read her health history in-take form at her local clinic. Although she did not let the cab driver help her, she was still angry over the situation. She stated, “My health stuff is private and so you know I still have a right to privacy when it comes to health stuff.” Few healthcare personnel gave the women the impression that they were aware of other means for gathering information from the women with VIs and they noted reluctance on the part of some personnel to help them. The reliance of healthcare providers on forms influenced access to health literacy because, “it makes you not even want to go to wherever it is, if you have to practically have to have an argument with the staff to get them to fill out something.”

The second mode of operation that influenced health literacy was related to the busy time schedules of providers. Asking providers to explain their behaviors and treatments took away from providers’ limited time. Hence, it was perceived that the providers were not always receptive to the women’s information needs because it would take more time to educate them. A participant stated, “If they’re making a big deal out of it and I can really tell that they truly are rushed and it’s really busy or whatever the situation. I’ve felt like, where they just go, ‘oh, gosh. I don’t have time for this blind woman,’ to try to give me a lesson or that kind of thing.”

Cultural and Societal Factors: The cultural and societal influences on health literacy were described by the women with VIs in two ways. First, ‘networks of support services’ were discussed. The networks of support services were informal and formal groups of family, friends, providers, and/or disability activists available to take action or give advice based upon interpretation of legal and healthcare issues. All of the women mentioned using various forms of information and support services that came from inside and outside of the health care system. One participant stated that she formed a team of providers to help her because multiple perspectives were needed to weigh the benefits and risks of healthcare decisions. She said, “I don’t think we should trust anybody with our health care until we’ve formed...what I did was form a team. Anybody who charges us, we should have a right to meet and we should demand to communicate with and decide if that is the person we want. And then my feeling, my approach, was I want to be head of this team until there may become a time that I can’t speak for myself.” Others relied primarily on family, such as the participant who referred to her husband when she said, “I rely on his eyes, yes. He sometimes relies on my brain.”

‘Environmental awareness’ was also a societal and cultural influence on health literacy. Environmental awareness was described in two ways. First, environmental awareness was described as messages about disability that influenced people’s reactions to women with VIs, which in turn, influenced what services or accommodations were made available to them. This was evident when a participant described how negative societal views about what

people with VIs were capable of doing affected her ability to take care of her health. She stated, “One thing that might diminish that is if we created an environment that made people aware that those curb cuts are important and this is why. The reading machines and the close circuit televisions in the library, if that stuff were more evident and everybody used it then it would become part of the culture. But attitudes far and away...and the battle to keep legislation current.” Second, environmental awareness was described as the individual woman’s awareness of her environment and her right to healthcare and accessible services. For instance, another participant stated, “it’s learning that you have rights and what your civil rights are and how to go about getting what you need and making sure that just because you have a disability, your rights aren’t violated. And so it comes down to just basic disability rights and personal civil rights stuff.” Overall, environmental awareness was the understanding that access to health literacy was influenced by societal and cultural messages about disability, and the women’s internal perceptions of those messages influenced whether the women would gain or seek what was needed to become health literate.

Factors in the Educational System: The women’s descriptions of how the educational system affected their health literacy needs were described under one main category: ‘developing life skills’. Life skills were described as the acquired skills for “how blind people can function.” Along with learning the necessary skills to communicate with accommodations such as Braille, Closed Circuit Television Systems, Screen Reader, and/or various technological devices for recording and re-playing information, the women discussed the need to have role models. Role models were those people with VIs that were able to function in society and demonstrate the subtleties of navigating the sighted world. Learning from role models with VIs was a necessary part of living and was primarily gained through specialized schools or programs for those with VIs. One participant stated, “If I had gotten services at home, in [public] school, I wouldn’t have gotten the blind living kind of stuff either. They probably wouldn’t have taught that. They would have taught the academics. I think it [school for the blind] was a good thing because that is how I got to learn how blind people can function and things like that.”

Ability to Obtain Health Literacy—Two main themes described the women’s ability to obtain health literacy: *barriers to necessary resources* and *facilitators of the necessary resources*. Barriers to necessary resources needed to achieve health literacy are those events, experiences, and circumstances that prevent, or make it more difficult, for women to directly acquire health literacy or the resources needed to achieve health literacy. Fourteen different barriers were noted by the women, which were lumped into either financial- or format-related barriers (Table 2). These barriers ranged from having few information sources in a format accessible to people with VIs to being unable to afford the cost of hiring a reader to read printed materials. These two types of barriers directly affected the ability to obtain health literacy, or they interacted such that one barrier would influence the other barrier. For instance, one woman stated that she had “devastatingly huge medical bills and there’s no end in sight. There never will be.” She was unable to hire a reader or gain information in Braille from her provider, which made her self-care complex and challenging. Similarly, health literacy was facilitated by having knowledge of how, where, and who to approach for health information, as well as the financial resources to buy equipment, such as a computer with a screen reader, which could be used to access health information.

Ability to Process—To process health information, the women needed literacy skills. The women who were visually impaired since birth or childhood claimed proficient use of Braille, Closed Circuit Television Systems, Screen Reader, and/or various technological devices for recording and replaying information. Women with later onset impairments, less than five years since onset, were in the process of acquiring literacy skills, such as the use of

Braille. Women also paid readers to provide them the information verbally. Hence, the main theme describing the ability to process information was related to possessing the prerequisite skill to read information with low or no vision.

In addition to literacy skills, the women stated that memory, cognitive skills, and attitude were essential to process health information. Memory was important because many things had to be memorized until the women had access to a Braillewriter, computer, or voice recorder for documenting their health instructions. Cognitive skills were essential for figuring out how health information pertained to their circumstance. For instance, one woman stated, “it comes down to you figuring out what you really need. That’s where you run into the problem because not everybody knows that. Not everybody knows what they need right at the moment that they need it.” Further, the woman’s attitude toward her vision loss and health influenced her ability to process health information as well. If the woman had the attitude that vision loss meant she was unable to care for her health, then she was less likely to process health information in a way that made her health literate; after all, she did not believe that she could control her health, so why learn about it? This was evident in the statement made by a 46-year-old woman that, “It’s (vision) loss that made me old and helpless. I don’t like being old and helpless. I don’t feel old and helpless, but the fact is, I am old and helpless and mostly because I can’t see what I’m doing. I need to be taken here and there. I can’t read...” The opposite attitude was displayed by an enthusiastic 79-year-old woman with adult onset macular degeneration, who showed the researcher the equipment she used with proficiency to process health information.

Ability to Understand: Putting Information in the Visually Impairment Context

—From these women’s experiences, it was ascertained that understanding was the holistic grasp of health knowledge as applied to the unique needs of aging women with VIs who were trying to maintain their functional health. These women did not report cognitive deficits and were highly educated. Hence, both the women and the researcher assumed that the women with VIs had the ability to understand basic health information when it was placed in the appropriate format. The women, however, were then responsible for adapting it to the context of someone who was visually impaired. The information had to be applied to their lives for the information to support their health, which is the difference between knowing about and taking-in information versus having a holistic grasp or understanding of health information. Two main themes described the women’s comments on their ability to understand: *contextualizing information* and *asserting needs*.

Contextualizing information for understanding was a process. First, when health information was available, the women recalled past experiences, treatments, and jargon in order to grasp how this new information fit into their lives. For instance, three women received treatments for problems that they did not wish to receive again and thus they avoided things that might put them at risk. A woman with a central line for chemotherapy stated, “Two weeks of intravenous Vancomycin, which I don’t want to do that ever again, so maybe I’m just over protective about it.” She understood that infection around the line led to a systemic infection and subsequently to the Vancomycin treatment, which she did not want due to lasting gastrointestinal side effects. Second, the women needed to know what the margin for error was in the context of any health related advice. For instance, one woman stated, “I’ve learned over the years to ask kind of what the margin is. Is this something that if it’s not exact, it is going to be problem? I don’t mean that I would just like to try to guess about what I was giving. But because I really did over the years try to develop systems to be as accurate as possible.” Contextualizing information is gathering information in relation to past knowledge and then assessing the risk involved.

Asserting her needs was how a woman reached a shared understanding between her and her provider. The women stated their problems in simple terms to their providers and asked that the provider explain it back in the same manner. One woman, who was diagnosed with late stage breast cancer despite yearly physicals, changed her approach to physicians based on her experience. She said, "I could have probably brought legal action for not having a mammogram for four years. I didn't, wasn't going to. I had more important things to do, but he didn't know it. So, I ask questions of the doctor. How do you feel about referrals?" At times, the women would "take a tape recorder" to document their requests and their provider's response. The women did this because "as soon as you're blind, your IQ is supposed to drop like 60, 70 points." By tape recording the conversation, providers were forced to attend to the women's requests. Next, they questioned when things were done to them that they did not understand. For instance, a woman stated, "I was miserable and here they are sticking me, which is the normal process. And he said...that's a standing order for everybody in the hospital. I said, 'what?' You know that made absolutely no sense whatsoever." Finally, asserting their needs was demonstrated by the women's insistence that uncertainty be diminished whenever possible—a process of continued clarification. They did this whenever information did not equate with their experiences, which caused a degree of uncertainty in their minds. A woman who did not receive physical therapy after her first back surgery began to demand services and explanations as further surgeries were required. She began to assert her needs.

DISCUSSION

According to the Model of Health Literacy Potential Intervention Points developed by the IOM (Figure 1), health literacy (i.e., the ability to obtain, process, and understand health information) is influenced by culture and society, health systems, and educational systems. Consequently, health literacy has a direct effect on health outcomes and costs (IOM, 2004). If persons with VIs are socialized through their interactions to relate with providers as helpless or dependent while being educated to survive using alternative means of communication frequently unfamiliar to the sighted majority (Scott, 1969), it is not surprising that they may have unvoiced healthcare needs, which are not being addressed by our healthcare system. The women in this study were taught to be highly independent in their daily lives, but perceived that they were treated as dependent and incapable of self-care when interacting with most providers.

The influences on health literacy, as described in the IOM model, also interacted to influence health literacy. Eleven of the women in this study had health insurance; only three had private work-based insurance. In the United States, this is important because people with VIs may be at a disadvantage in terms of access to health information and services because working-aged persons with VIs are less likely to have any type of health insurance when compared to those without VIs (Chiang, Javitt, Metrick, 1994). The difficulty that these women with VIs may have had accessing health information may have been made worse by their lack of private insurance. The women described how the assumptions that they were on government assistance and cognitively impaired made it difficult to communicate with providers in way that enhanced their health literacy. This poor interaction with providers was one way that the health care system interacted with societal and cultural views to affect health literacy as indicated in the IOM model.

Some might suggest that if a woman had difficulty interacting or communicating with providers she might use the Internet to gain information. For these women with VIs, this may not be an option. First because of the cost associated with gaining this type of equipment. The women discussed financial constraints as a major barrier to health. Further, as recently as 2002, only 19% of health information Web sites were accessible to those with

VIs (Davis, 2002). The paper formats, free to most people with normal visual acuity, were costly to these women because they had to hire a reader, scan it into a computer, or use a screen reader or their CCTV, to read it.

The framework for health literacy with intervention points produced by the IOM, coupled with the findings from the current study, may serve as a starting point from which to improve care for women with VIs. The IOM framework indicates that health care systems can have an effect on health literacy. Hence, providers might improve care and health literacy by educating themselves and other healthcare personnel on how to interact with persons with VIs in ways that facilitate health literacy. For instance, these women thought it would be helpful if instructions were directed to them, and that it never be assumed that other caregivers were responsible for their medical care or decisions because they had a VI. When the health care system perpetuates societal stereotypes of women with VIs as dependent, it undermines their ability to remain independent community-residing individuals and may jeopardize their health outcomes. Indeed, a recent analysis of adjustment to age-related vision loss demonstrated that perceived overprotection of persons with VIs was associated with lower adaptation and environmental mastery (Cimarolli, Reinhardt, & Horowitz, 2006).

Evidence suggests that in our society, the achievement of literacy may be more of a challenge for persons with VIs than for sighted individuals (McCall, 1999). Theoretically, this is because of the constant visual stimuli that sighted individuals receive reinforcing visual print materials. This appears to hold true in studies related to the education of low health literate individuals; Schwartzberg, Cowett, Vangeest, and Wolf (2007), for example, recently reported that drawing pictures was one of the most effective and underused techniques for educating low health literate individuals. However, the way in which vision is used to construe the world might create varied understandings of content in sighted persons versus those with VIs (Argyropoulos & Martos, 2006). In other words, the medium used to convey messages might create differences in how the messages are understood, which may affect how people with VIs understand health messages that are usually designed for and conveyed to sighted people. This does not mean, however, that health messages should not be conveyed to foster self-care in persons with VIs. It means that more research is needed to explore health literacy in persons with VIs and translate new strategies into practice and give them the tools to live long and healthy lives. Indeed, one woman who was completely blind since birth stated that because sighted providers cannot imagine doing things without the ability to see, they believe it cannot be done. Then she demonstrated how she independently checks her blood sugar with a monitor on a daily basis.

Further research is needed about how to combine the knowledge and technology created by the educational system for persons with visually impairments with the educational system for healthcare providers. Team efforts that include specialists in the delivery of knowledge to people with VIs give providers the best tools for communicating with people with VIs. These collaborations are needed before medical emergencies or even routine visits occur. Finally, studies about the influence of health literacy on health outcomes among persons with VIs are needed. Researchers should also consider that health information processing skills, educational attainment, and information needs may vary between genders (Hill & Needham, 2006).

It may take more time from providers to interact with women with VIs on a level that promotes health literacy. These women perceived that most of the onus of ensuring their ability to obtain, process, and understand general health knowledge was on them. Given the possibility that accommodations for persons with VIs may not be common knowledge among general practitioners, work may be needed to improve the way that health

information is provided so that multiple means of communicating health information would be the standard of care. As a starting point, a list of strategies for working with women with VIs is presented in Table 3. A helpful resource for healthcare providers might be a recent publication about VIs, which was edited by Houde (2007). In the meantime, time invested in building health literacy capacity among people with VIs may actually decrease costs if poor health due to medication errors and/or misinterpreted instructions is prevented.

The findings of this study are limited to the experiences of 15 women with VIs. The women were highly educated, mostly Anglo, and belonged to a disability community within an urban area. Those with cognitive impairments and men were not included in this study. These findings were not meant to generalize to all persons with VIs. Those living in rural areas, for instance, may not have access to a disability community and similar resources; therefore, they may have a different experience with health literacy. Further, the women in this study had been living with VIs for three to 58 years. They reported variations in reading mediums, as well as levels of expertise with those mediums. For example, one woman was currently receiving instruction on the use of Braille, while others were very comfortable with it. Moreover, it was beyond the scope of this study to test the women's current levels of literacy objectively or the accuracy of their understanding of medical terminology and/or instructions. This study was an analysis of their perceptions only.

In conclusion, if the goals set by Healthy People 2010 are to be met, further work is needed on ways to improve the ability of persons with VIs to promote their health. One possibility may lie in the advancement of health literacy, which could ensure the ability of persons with VIs to critically analyze and manage their personal health outcomes. These interviews about health promotion with 15 women with VIs who lived independently in their communities support this assertion. For these women, health literacy was reportedly improved when they came to an understanding of general health goals, along with ways to apply those goals to their lives, which required sensitivity to their unique circumstances as women with visual impairments, as well as the appropriate accommodations. This allowed them to make critical decisions regarding their health, enhancing their sense of independence. Regretfully, there is little evidence that the health care system has made efforts to respond to the health literacy needs of persons with visual impairments.

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Figure 1.
The Institute of Medicine's Health Literacy Framework with Potential Intervention Points.
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Table 1

Definitions of vision related concepts

Concept	Definition
Blindness	$<6/120$ [$<20/400$] ¹ as defined by the World Health Organization (WHO) or $\leq 6/60$ [$\leq 20/200$] ¹ as defined by the United States Medical Consensus
Low Vision	$<6/12$ [$<20/40$] ¹ as defined by the United States Medical Consensus The WHO (2009) states that low vision is “impairment of visual functioning even after treatment and/or standard refractive correction, and has a visual acuity of less than 6/18 to light perception, or a visual field of less than 10 degree from the point of fixation, but who uses, or is potentially able to use, vision for planning and/or execution of a task.” Or The self-report of limitations such as: “The inability to recognize a friend across the room, even when wearing glasses or contact lenses” (Houde, 2007, p. 2).
Visual Impairment	Meets either definition of low vision or blindness.
Legally blind	Although only useful for the sorting of social benefits within a society, legal blindness is “typically defined as visual acuity with best correction in the better eye worse than or equal to 20/200 or a visual field extent of less than 20 degrees in diameter” (Prevent Blindness America, 2008, p. 4).

Notes:

¹ The numerator in the above terms refers to the distance at which a person being tested visually recognizes the symbol being presented, while the denominator refers to the distance at which a person with normal visual acuity could recognize the symbol being presented (Scheiman, 2002). When a person has 20/20 vision, they are said to have normal vision. When a person has 20/100 vision, they are said to see at 20 feet what a person with normal vision could see at 100 feet.

Table 2

Some barriers to necessary resources needed to achieve health literacy

Category	Barrier
Financial	<ol style="list-style-type: none"> 1 Cost of health care resources perceived as too high. 2 Too many other non-health related bills in their lives so cannot afford accommodations. 3 No pension or security for later life, need to save money. Cannot spend money on accommodations at this point in life. 4 High cost of transportation to go searching for information. 5 High cost of personal care help and readers to gain information. 6 Other health related needs must be bought first. For instance, need to buy mobility aids first before gaining access to health promotion related materials.
Format	<ol style="list-style-type: none"> 1 Forms to gain access to providers were in paper format—unable to see written words to complete forms. 2 Cannot read referral information on health care providers to initiate new professional help when needed. Unaware of who is knowledgeable or appropriate to talk to in the community. 3 Complaints about format risk loss of health care providers' attention or good will. 4 Information in appropriate formats are out of date in relation to current medical knowledge 5 Community health information on various professional services is not available in appropriate formats; cannot browse the yellow pages 6 Experiences in which healthcare providers reacted badly or were "hassled" when they are were asked to provide things in format needed. Hence, participants refuse to ask for correct format again. 7 Providers 'stuck' in one way of providing paperwork and unaware of other methods 8 Loss of privacy when reading paperwork aloud—others know what you need information about when someone has to read it to you.

Table 3**Strategies to Improve Health Literacy among Persons with Visual Impairments**

Strategies for providing care to those with visual impairments.
Assess the accessibility of health information Web sites to those with visual impairments before recommending them.
Provide a private area for verbal disclosure of private health information.
Ask people before their appointment if they have a visual impairment that may require accommodations. Then ask what accommodations they might need so that advance preparation can be made for their needs.
Learn and provide appropriate sighted-guidance for those with visual impairments. Educate other health care providers on sighted-guide techniques and the meaning of a white cane.
Never assume that people with visual impairments have caregivers.
Compile a list of medical suppliers such as pharmacists that provide information in Braille.
Consider providing educational materials in Braille, large print, and electronically. Ask what type of materials would be preferred by an individual with a visual impairment.